At-home Use of a Computer-based Pointing Task Accurately and Reliably Estimates Motor Impairments

ANONYMOUS AUTHOR(S)

Obtaining valid, reliable, and low-burden quantitative assessment of motor impairments is a key challenge in the longitudinal care of people with motor impairments. Assessments with specialized instruments in controlled settings produce high-quality measures of motor performance; it remains unknown if similar measures can be obtained using common technologies in the home environment. We contribute to this body of research by evaluating the validity, reliability, and acceptability of at-home use of a recent computer-based system, called Hevelius, for quantifying motor impairments in the dominant arm. Hevelius presents pointing tasks, computes 32 measures from users' mouse movement trajectories, and reports age-specific z-scores; the z-scores separate the effects of a motor impairment from the effects of development/aging. In our study with participants with a pediatric movement disorder, Hevelius measures from at-home use demonstrate strong test-retest reliability (ICC = 0.9) and produce estimated severity scores correlated with clinician-assigned severity scores (r=0.67). Additionally, the participants and their caregivers found the tool simple to use. Our results highlight the promise of obtaining reliable quantitative assessments of motor impairments in unsupervised settings.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**.

Additional Key Words and Phrases: remote assessment, neurological disorder, telemedicine

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1 INTRODUCTION

Obtaining valid, reliable, and low-burden quantitative assessment of motor impairments is a key challenge in longitudinal clinical care, in medical research, and in design of accessible technologies [17, 38]. Technology-supported approaches for producing high-quality quantitative assessments demonstrate trade-offs in quality of measurements and costs/efforts; they are promising when performed under researcher supervision in controlled settings but produce data is noisy and difficult to interpret in natural environments. At home assessments can be cheaper and more accessible; furthermore, such assessments might reflect behavior in more realistic settings than the lab [14]. However, the measurements might be of low quality due to imperfect compliance with instructions, possibility of interruptions, and diversity of hardware and contextual settings [9, 14]. This paper tackles the problem of collecting valid and reliable measures of motor impairments without researcher supervision in real-world environments.

To address challenges with compliance and patient motivation at home, passive tracking efforts capture and quantify natural use by instrumenting computer use and collecting data from smartphone sensors and specialized hardware [17]. While these approaches reduce patient burden, they might still require expensive devices–such as specialized sensors–or produce data that are difficult to interpret [27]. Thus, despite considerable progress, there is still no consensus on how

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to perform high quality assessments of motor impairments in natural environments like home. We contribute to this body of research by evaluating the validity, reliability, and acceptability of at-home use of a recent computer-based system, called Hevelius, for quantifying motor impairments in the dominant arm.

Hevelius presents patients with pointing tasks and analyzes the trajectories of the mouse movements they perform. Hevelius computes 32 measures from the movement trajectories, many of which have been introduced or used by HCI researchers [14, 15]. Unlike previous approaches, Hevelius reports measures as age-specific z-scores computed in comparison to a normative data set obtained from more than 200,000 healthy controls. Because motor abilities change substantially throughout a person's lifetime, the age-specific z-scores reported by Hevelius make it possible to separate the effects of a disease from the effects of development or aging. To relate the measures produced by Hevelius to clinically-meaningful ground truth, a regression model has been developed and validated for estimating the severity scores of ataxia patients (using the Brief Ataxia Rating Scale, or BARS) from the measures reported by Hevelius.

We conducted a study involving 18 children with Ataxia-telangiectasia (A-T) and 14 healthy children. The children with A-T were assessed by a clinician. They also used Hevelius once on researcher-provided equipment and under researcher supervision. Subsequently, the children used Hevelius at home–on their own computers and without researcher supervision–once a week for up to 12 weeks. Our results demonstrate that severity scores estimated by Hevelius from at-home sessions correlated with severity scores assigned by the clinician as well as the severity scores estimated from the sessions when the children used Hevelius under researcher supervision. These findings demonstrate that unsupervised use of Hevelius produces data that are as valid as the data obtained in supervised settings. Further, the data obtained at home demonstrate strong test-retest reliability (ICC = 0.9). Lastly, the patients and their care givers found the tool acceptable. Taken together, our results contribute evidence that it is possible to obtain valid and reliable quantitative assessments of motor impairments in unsupervised settings.

2 RELATED WORK

In this section, we summarize research from technology-supported approaches to quantify motor impairments across different settings.

2.1 Quantitative assessments of motor impairments across lab and home

Accurate and reliable assessments of motor impairments can benefit clinical work, medical research, and the design of accessible technologies [12, 17, 38]. Technology-supported assessments in lab/clinical settings have produced high quality measurements. Wearable sensors track movement data using accelerometer (for movements), gyroscope (swinging, turning), and electrocardiography (heart rate/rhythm to classify intense vs light exercises) [24]. Finger tapping tasks on touchscreens can distinguish people with Parkinson's Disease from healthy controls [3]. While such approaches produce quantitative measures of motor impairment, they rely on expensive hardware (like sensors) and researcher supervision. At home assessments can be cheaper and more accessible; furthermore, such assessments might reflect "natural" behavior [14]. However, in the absence of researcher supervision and controlled settings, the measurements might be of low quality. People might not comply with the instructions, come across interruptions, or use devices in settings that don't yield useful data [15].

To reduce participant burden, common consumer devices have been used to create quantitative representations of motor impairments. Passive tracking captures and quantifies natural performance by instrumenting computer use, tracking smartphone sensors, and using specialized hardware [17]. Such efforts–an instance of digital phenotyping [17, 28]–have expanded our understanding of movement disorders in the real world. Keystrokes derived from typing on a

laptop identified response to dopamine therapy [26]. More recently, a single wrist sensor has been shown to provide accurate, reliable, and interpretable information about the severity of motor impairments in a rare pediatric disorder [19]. Such approaches reduce logistical and cognitive burdens: participants don't need to visit a lab/clinic or alter their behavior. Since the data is tracked during free-living activities, however, it might be noisy and difficult to interpret [27]. Additionally, such approaches might still require devices or sensors that are not easily accessible to many. To the best of our knowledge, there is no consnsus on how to perform high-quality assessment of motor impairments beyond supervised settings with readily accessible technologies. We contribute to this body of research by evaluating the validity, reliability, and acceptability of at-home use of a recent computer-based system, called Hevelius, for quantifying motor impairments in the dominant arm.

2.2 Pointing tasks have assessed motor impairments in controlled settings

Cost-effective, frequent, and unobtrusive assessments of motor performance during everyday computer use is an important goal in accessibility research [14]. One common technique for quantifying people's motor performance while using a device is analyzing a user's performance on *pointing tasks* where people move the cursor to indicate a particular target [14]. For personal computers, trajectories and events from such mouse-based pointing task are converted to features [7, 9]; such features are then compared across people with motor impairments and age-matched healthy controls. Prior research has developed multiple measures that discriminate between healthy controls and people with motor impairments. For instance, individuals with Mild cognitive impairment (MCI) demonstrated fewer total mouse movements and greater variability in duration of pauses between mouse movements [34]. Velocity profile (speed, acceleration, and jerk) can help distinguish deliberate, targeted pointer movements from "noisy" ones that are more common in those with motor impairments [9]. Additionally, participants with motor impairments make more curved and looped movements in their mouse trajectories. Many such features are naturally informative for clinical assessments of motor impairments. For instance, participants with a motor phenotype called ataxia make oscillatory movements during the finger to nose test; such movement results from over- and undershoot of the target and is called dysmetria.

While quantifying and using features from pointing tasks have been useful in the lab setting, two bottlenecks limit such techniques' utility in assessing motor impairments more pervasively. First, such assessments have been performed under researcher supervision; the quality of unsupervised pointing tasks is less understood. People's performance on pointing interactions in natural settings differs substantially from those in lab settings [9]. Participant's motor abilities might change over time due to "medication, fatigue, and changes in the underlying medical condition" [15]. Performance might even change across usage device: user interface evaluations with paid remote participants yield the same conclusions as in-lab studies for desktop interfaces [20], but not necessarily for mobile interfaces [8].

Second, such studies require age-matched healthy controls. Because motor abilities change substantially throughout a person's lifetime, data from age-matched health controls enables separating the effects of a disorder from the effects of development or aging. More recently, supervised assessments with a computer-based system, called Hevelius, have quantified motor impairments in the dominant arm [10]. Hevelius presents patients with pointing tasks and analyzes the trajectories of the mouse movements they perform. Hevelius computes 32 measures from the movement trajectories, many of which–e.g. changes in movement direction, noise-to-force ratio–have been introduced or used by HCI researchers [25, 36]. Unlike previous approaches, Hevelius reports measures as age-specific z-scores computed in comparison to a normative data set obtained from more than 200,000 healthy controls. The age-specific z-scores reported by Hevelius make it possible to separate the effects of a disease from the effects of development or aging. In

terms of study pragmatics, age-specific z-scores reduce the burden on unsupervised assessments by removing the need to find age-matched healthy controls.

While Hevelius' utility under researcher supervision is promising, acceptability and value of unsupervised sessions is unknown. Three questions remain: 1) How well do measures form unsupervised sessions estimate existing ground truth?; 2) How well do estimates over the measures compare across supervised and unsupervised settings?; and 3) Are such measures reliable over unsupervised sessions? We contribute a rigorous evaluation of the validity, reliability, and acceptability of unsupervised assessments for pointing problems with a rare disorder community.

2.3 At-home use of Hevelius by participants with a rare neurological disorder

Ataxia-telangiectasia (A-T) is a progressive, life-limiting neurological disorder. Typically apparent during childhood, this disorder is characterized by impaired coordination of movement, impaired immunity, increased cancer risk, and telangiectasias (small widened blood vessels). Since it affects multiple body systems, A-T requires a complex care team comprising multiple specialists making it extra daunting for caregivers to both understand and manage the condition.

Valid, reliable, and low-effort at-home assessments of motor impairment can potentially benefit A-T families. A-T is a *rare disorder*; rare disorders are disorders that affect fewer than 200,000 people. This quantitative distinction in the number of patients leads to differences in the availability of experts (both in numbers and location), quality of care, general awareness about the condition, and the current state of research [16]. For instance, a clinical trial for a rare disorder enrolled just 39 patients in 10 years [22]. At-home assessments can potentially improve patients' access to better medical research. However, there are challenges in conducting at-home assessments with pointing tasks for participants with A-T. Since A-T is a pediatric disorder, any assessment needs to be appropriate for cognitive and motor skills of children. Since the assessments happen at home, any issues due to a mismatch between participants' abilities and tool's expectations might not be debugged as quickly as the lab setting. A tool for assessing motor impairments in such settings would need to be robust and easy-to-use; possible customization based on user's abilities would be further beneficial. Finally, younger participants might lack the necessary knowledge or articulation capabilities to share contextual factors (like mood or interruptions) that might be needed to accurately assess their performance.

3 HEVELIUS FOR AT-HOME ASSESSMENTS

Hevelius comprises a computer mouse-based tool that provides objective, granular, interpretable, quantification of motor impairment in the dominant arm with a few minutes of use [10]. Hevelius presents participants with pointing tasks, collects movement data, and computes 32 measures (Table 2). The measurements are reported as age-specific z-scores by comparing them to baseline data collected from health volunteers of the same age. Hevelius is accessed

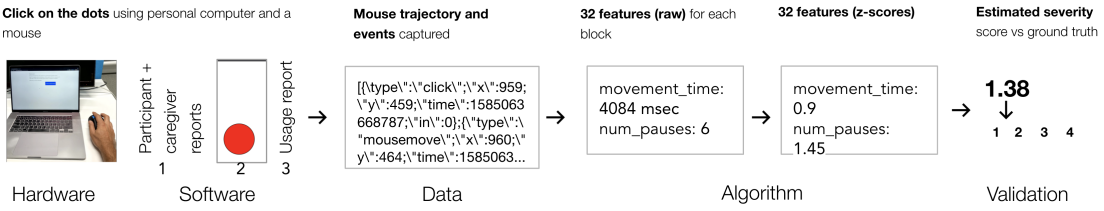

Fig. 1. Families with A-T access Hevelius at home using a mouse and a browser on a personal computer. Activities comprise pointing tasks and reports from participant & caregivers. Supplementary material provides the complete list of 32 Hevelius measures. Figure inspired by Figure 3 in [37].

using an online browser on a personal computer and the pointing tasks are performed using a mouse. Supplementary methods in a previous publication elaborate on Hevelius' design and techniques for data collection and processing [10]. In this section, we summarize Hevelius' pointing task and movement data processing.

3.1 Pointing task

Participants use the mouse to click on a target (presented as a red circle) as accurately and quickly as they can after it appears. When clicked correctly, the clicked target is replaced with another target. Clicking on one target comprises a complete trial; a sequence of nine targets constitutes a block. Participants can take a break between blocks; they're instructed to completed each block without interruption. Targets in a block are of the same size; targets across blocks are selected over multiple target sizes. The distance between successive targets in a block is the same.

3.2 Movement Data Processing

Participants' mouse movement is represented as basic movement statistics (location of endpoints, timing) as well as detailed movement trajectories. Each movement is decomposed into several components including initiation (from the target onset to the first mouse move event), execution (from first to last mouse move event), verification (time spent inside the target between last mouse move event and the start of the click), and click (mouse down to mouse up event). 32 measures computed from the movement components are converted to age-specific z-scores by comparing the movement features to those from healthy online volunteers of the same age.

3.3 Instrumenting Hevelius for at-home assessments

Four components were added to the in-clinic version of Hevelius. Two components–caregiver reports and participant self-reports–are presented to the participant before the pointing task (Figure 2). Caregiver reports sought responses about participants' well-being; prompts included 5-point scale about tiredness and degree of co-operation; and a numeric response scale for significant events (stumbling or tripping) since last use of Hevelius. Participant self-reports sought responses about mood, alertness, and sleep on a 5-point Likert scale; the scale was shown with large face icons to make the options more accessible to children. Like the previous version, pointing tasks comprised two practice blocks and eight task blocks. Unlike the previous version of Hevelius–where the target sizes varied from 20 pixels to 60 pixels–Hevelius for at-home use had target sizes vary from 16 pixels to 90 pixels. The third component is an option for participants to select a target size as the minimum target size across all sessions. The fourth and final component is caregivers' usage reports after the pointing task; these included categorical responses (for length of

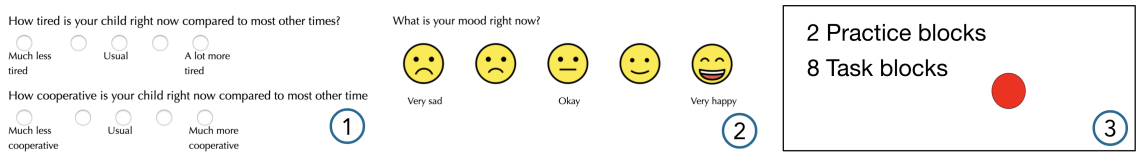

Fig. 2. Summary of At-home version of Hevelius. 1) Caregivers provide reports on participants' well-being as a 5-point Likert scale and numeric responses. Prompts included tiredness and degree of co-operation; and a numeric response scale for significant events (stumbling or tripping) since last use of Hevelius. 2) Participants provide self-reports for mood, alertness, and sleep; and 3) Participants perform pointing tasks. Pointing tasks comprised two practice blocks and eight task blocks.

the task, interruptions, and other issues) and comments (on length and ease of the task, interruptions, and technical difficulties). Hevelius is implemented in PHP, HTML, and Javascript and hosted online at [anonymized].

4 STUDY

An longitudinal study of at-home use of Hevelius evaluated whether Hevelius produces valid, reliable, low-burden measures from longitudinal use at home. Participants comprised children with A-T and healthy controls.

4.1 Research Questions

Our study addressed three research questions to understand the validity, reliability, and acceptability of Hevelius at home.

(1) Do Hevelius' measures provide valid assessments from at-home use?
   (a) Do Hevelius' measures from at-home use accurately estimate clinically-meaningful ground truth?
   (b) How well do Hevelius' measures from at-home use compare to supervised use for estimating clinically-meaningful ground truth?
(2) Do Hevelius' measures provide reliable assessments from at-home use?
   (a) Do Hevelius' measures from at-home use reliably estimate clinically-meaningful ground truth?
   (b) How reliable are Hevelius' measures?
(3) What challenges are faced by families in using Hevelius at home?

4.2 Methods

Our study has two components: 1) Supervised use: using Hevelius once (on researcher-provided equipment and under researcher supervision), and 2) At-home use (on personal computers without researcher supervision) once a week for 12 weeks.

4.2.1 Supervised use. All participants with A-T completed clinical assessment followed by using Hevelius along with their caregivers. Clinical assessment comprised recording video data for a neurological exam; this video was later used by a clinician to assign *severity scores* to participants' motor impairment in the dominant arm based on the Brief Ataxia Rating scale (BARS) [32]. All healthy controls were assigned BARS scores of 0. While using Hevelius, participants had the choice to increase the target size in the second practice task if they felt the smallest target size (16 pixels) was too small; the selected target size was used as the minimum target size across supervised and at-home assessments for the participant. Two members of the research team were present during participants' supervised use to answer any questions. The research team suggested families use at-home Hevelius once a week for up to 12 weeks and encouraged them to note a day and time of the week for using the tool. Researchers provided families with a USB 3 Optical Mouse [1] for at-home use; in some cases, families mentioned they were comfortable using their mouse. Caregivers were told that they could communicate with two members of the research team via emails if they faced any issues.

4.2.2 At-home use. Participants and caregivers used Hevelius without supervision on their personal computers using a mouse. A partner organization sent two emails to all participating families: 1) a reminder mail 2 weeks after their supervised use; 2) a summary of researchers' response to questions from the families. The research team met weekly to share weekly usage data, identify outliers, and discuss usability changes to the tool. If a family did not use the tool for

[1] https://www.amazon.com/gp/product/B0029L0IM8/

Table 1. Participant demographics. A total of 32 A-T and healthy controls were enrolled in the study. The severity scores represents the severity assigned by a clinician for the dominant arm on the Brief Ataxia Rating Scale (0–4).

Diagnosis	N	Age		Sex		Handedness		Severity Score
		Median	Range	Female	Male	Left	Right	Scale: 0-4
A-T	18	10	[4,15]	8	10	2	16	0.5-3 (M: 2.03, SD: 0.74)
Control	14	11	[4,16]	5	9	1	13	0

two weeks, the research team updated the designated contact person at rare disease foundation whose team reached out to the caregivers (over email/phone) to understand concerns (if any).

4.3 Participants

4.3.1 Approval. Written informed consent and assent were obtained from all participants prior to participation. This study was approved by the Internal Review Board at [anonymized]. Participants received a $50 American Express gift card.

4.3.2 Recruitment. Thirty-two children—eighteen with A-T, fourteen without–were enrolled in the study (Table 1). Identified healthy controls were siblings of the A-T participants. All participants were identified in partnership with the Ataxia-telangiectasia Children's Project (A-TCP) which is a 501(c)(3) nonprofit organization that supports biomedical research projects for Ataxia-telangiectasia (A-T)[2]. All children with A-T were genetically confirmed to have the disorder. Children were excluded from the study if they were younger than 4 years old, unable to perform the computer mouse task, and demonstrated another movement disorder or other condition that affects arm function or mobility. The median age of A-T and healthy controls was 10 and 11 years respectively. Three participants, one control and two with A-T, indicated that their left hand was their dominant hand.

4.3.3 Data collection and analysis. Data was collected between January and September 2020. Three participants with A-T (between the ages of 4 and 10) did not receive clinical assessment; four participants with A-T did not use Hevelius in supervised setting; one participant did not use the tool at home. Of these eight participants, five were not cooperative, tired, or resting during different activities of the supervised use; one participant was enrolled too late in the day to perform the clinical assessment; one participant did not receive clinical assessment due to escalation of the COVID-19 pandemic; and another participant–who did not perform at-home assessments–did not report back to follow-ups. Two healthy controls did not performed at-home use. Data from an at-home session was excluded if the session produced measures that was null/outlier. An outlier is a value that does not fall in [Q1 - 1.5 IQR, Q3 + 1.5 IQR]. Data from the first eight at-home sessions were used in analyses; participants' attrition is shown in Figure 3A. Analyses was performed using R, Microsoft Excel, and JMP.

4.4 Measures

Hevelius features were computed from each session. Supervised use of Hevelius produced a z-score for each Hevelius feature. Where needed, median over at-home sessions' data was taken to produce a z-score for each Hevelius feature for at-home use.

[2]We refer to A-TCP as rare disease foundation in the text

4.4.1 Validity of Hevelius' measures. Measures comprised

(1) Pearson correlation (r) between severity scores estimated from at-home use of Hevelius and severity scores assigned by a clinician (ground truth) for participants with A-T
(2) Pearson correlation (r) between severity scores estimated from supervised use of Hevelius and severity scores assigned by a clinician (ground truth) for participants with A-T

We developed a regression model for estimating the severity scores of participants with A-T (using the Brief Ataxia Rating Scale, or BARS, for dominant arm) from the measures reported by Hevelius. As per common heuristics [33], we interpreted Pearson's correlation (r) using the following thresholds: 0.00–0.10: Negligible; 0.10–0.39: Weak; 0.40–0.69: Moderate; 0.70–0.89: Strong; 0.90–1.00: Very strong.

4.4.2 Reliability of Hevelius' measures. Measures comprised

(1) the test-retest reliability of severity scores estimated from Hevelius' measures over at-home use for children with A-T and healthy controls;
(2) the test-retest reliability of the 32 measures over at-home use for children with A-T and healthy controls.

Reliability of estimated scores and 32 Hevelius measures was computed as Intraclass Correlation Coefficient and their 95% confidence intervals calculated using R with irr package based on a single rating, absolute-agreement, 2-way mixed-effects model. Estimated scores were compared one session, two sessions, and four sessions at a time. The measures were compared four sessions at a time. As per common heuristics [21], we interpreted the Intraclass Correlation Coefficient

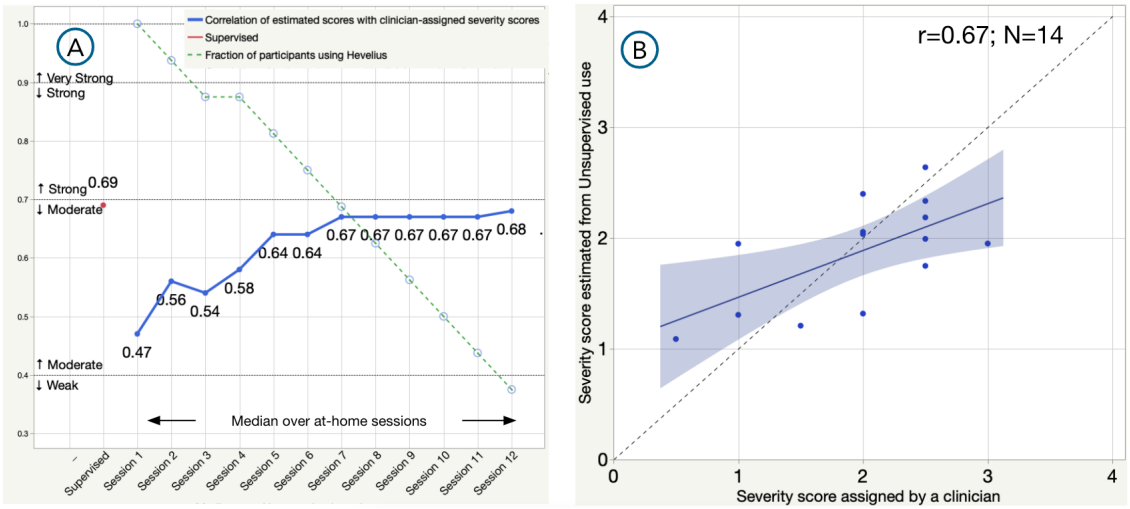

Fig. 3. Severity scores estimated from at-home assessments were compared to severity scores assigned by a clinician. (A) Pearson's correlation between scores estimated from the first S at-home sessions (where $1 \leq S \leq 12$) and clinician-assigned severity scores. Scores estimated from more at-home assessments were better correlated with clinician-assigned severity scores. The dashed line shows the fraction of participants using the tool over at-home sessions. (B) Estimated scores correlated moderately with clinician-assigned scores (r=0.67; F(1,12) = 9.91, p=0.0084). Scatter plot shows the data. Linear regression line is shown in blue. The dashed y=x line is shown for comparison. The shaded bands represent the 95% Confidence Interval. Pearson correlation coefficient (r) and number of participants (N) are shown.

(*ICC*) using the following thresholds: 1) below 0.50: poor; 2) between 0.50 and 0.75: moderate; 3) between 0.75 and 0.90: good; 4) above 0.90: excellent.

4.4.3 Acceptability of at-home assessments. Measures comprise 1) Time taken on the pointing task; 2) Participant self-reports and caregiver reports on health; 3) Caregiver reports (length of task, interruptions, issues).

5 RESULTS

14 participants with A-T received a severity score from a clinician and used Hevelius at home for at least one session (median: 9 sessions; range: 4 to 12 sessions). 11 A-T participants received a severity score from a clinician and used Hevelius under researcher supervision. 9 healthy controls used Hevelius at home and in the supervised setting.

5.1 Hevelius' measures provide valid assessments from at-home use

5.1.1 Estimated scores from at-home assessments are moderately correlated with clinician-assigned scores. Including more at-home sessions improved the correlation between estimated scores with clinician-assigned severity scores (Fig. 3A). Our regression model found that estimated severity scores for at-home sessions correlated moderately (r=0.67; $F(1,12) = 9.91$, $p<0.01$) with the clinician-assigned severity scores for the dominant arm on the Brief Ataxia Rating Scale (Fig. 3B). The Bland-Altman plot for estimated scores and clinician-assigned scores showed mean difference of 0.13 between estimated scores and clinician-assigned scores with 95% Confidence Interval in [0.9,-1.18] (Fig. 4B - blue).

5.1.2 Estimated scores from at-home assessments and supervised assessments are similarly correlated with clinician-assigned scores. We found two results Clinician-assigned severity scores correlated similarly with estimated scores

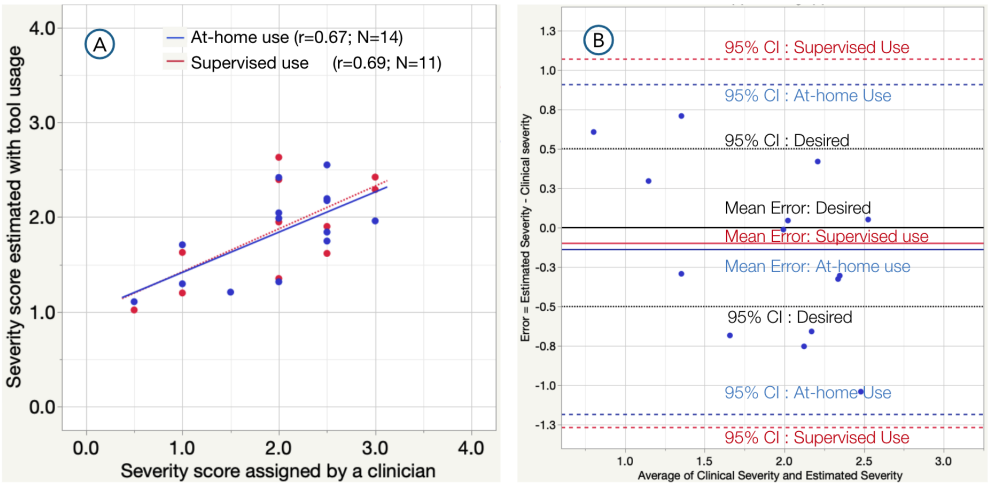

Fig. 4. (A) Severity scores estimated from supervised and at-home use were plotted against the severity score assigned by a clinician. Linear regression line is shown (blue for at-home use and red for supervised use). Pearson correlation coefficient (r) and number of participants (N) are shown. (B) Estimated scores and clinician-assigned severity scores were plotted using the Bland-Altman plot to visualize their difference. Scatter plot shows the data points (x,y) for at-home use; the data points were created by calculating the average and difference of the two scores. Solid lines represent the mean and dashed lines represent the 95% Confidence Interval. Blue represents at-home use; Red represents supervised use; Black represents desired mean error and 95% Confidence Interval. CI = Confidence Interval.

from at-home use (r=0.67; F(1,12) = 9.91, p=0.0084) as with supervised use (r=0.69; F(1,9) = 8.09, p=0.02) (Fig. 4A). The Bland-Altman plot for supervised sessions showed mean difference of 0.09 between estimated scores and clinician-assigned scores with 95% Confidence Interval in [1.06,-1.26] (Fig. 4B - red). Compared to at-home sessions, the mean difference is lower by 0.04 points and the 95% Confidence Interval limits is higher by 0.24 points.

5.2 Reliability of estimated scores among participants with A-T and healthy controls

Fig. 5A shows the per-participant distribution of the estimated scores.

5.2.1 Estimated scores from at-home assessments demonstrated moderate test-retest reliability among participants with A-T. Moderate reliability was found between the eight sessions' estimated scores from the A-T participants when taken one at a time. The reliability improved to excellent when at-home sessions were taken four at a time (Fig. 5B);
(one session at a time) ICC(A,1) = 0.744, 95% CI [.554, .905]; (two sessions at a time) ICC(A,1) = 0.87, 95% CI [.72, .958]; (four sessions at a time) ICC(A,1) = 0.9; 95% CI [.679, .972].

5.2.2 Estimated scores from at-home use demonstrated moderate to good test-retest reliability among healthy controls. Moderate reliability was found between the eight sessions' estimated scores from healthy controls. The reliability improved to excellent when at-home sessions were taken four at a time (Fig. 5B);
(one session at a time) ICC(A,1) = 0.596, 95% CI [.346, .857]; (two sessions at a time) ICC(A,1) = 0.814, 95% CI [.584, .948]; (four sessions at a time) ICC(A,1) = 0.911, 95% CI [.652, .979].

5.3 Many features from at-home use demonstrated good test-retest reliability among both A-T and controls participants

Basic aspects of performance demonstrated good reliability among both participants with A-T and healthy controls. Such aspects include overall efficiency (measured by movement time; ICC(A,1)=0.985 (participants with A-T), 0.931 (healthy controls) and the ability to control movement speed (measured by normalized jerk; ICC(A,1)= 0.799 (participants with

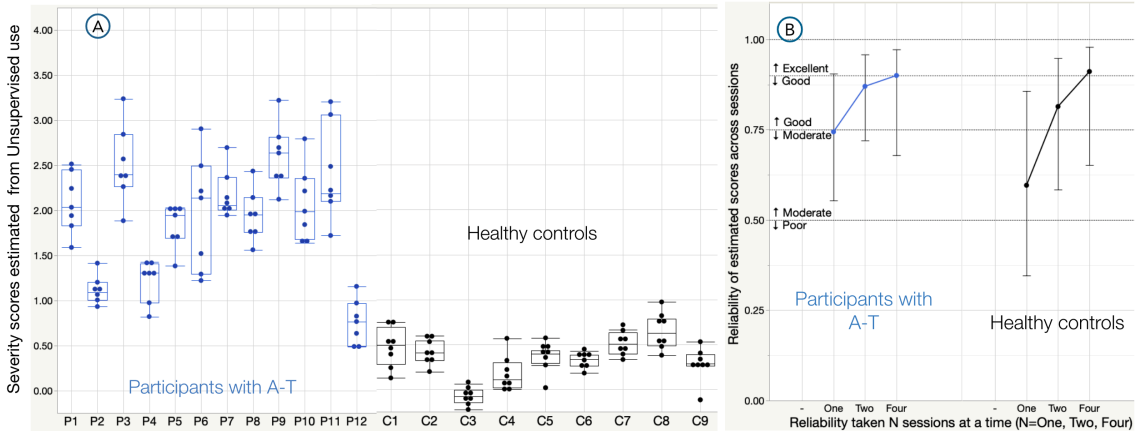

Fig. 5. (A) Participant-wise distribution of estimated scores from at-home assessments for participants with A-T and for controls (B) Test-retest reliability was moderate for participants with A-T (ICC=0.839) and for controls (ICC=0.707) participants when sessions were compared individually. Reliability improved to good for both A-T (ICC=0.855) and Controls (ICC=0.874) participants when comparisons were made four sessions at a time.

Table 2. Hevelius features (with moderate and high reliability) sorted in descending order of reliability for A-T participants. Intraclass Correlation is also shown for controls participants for comparison. A list of all 32 features with their reliability is provided in the Supplementary material.

#	Feature name	Feature description	ICC (A-T)	ICC (Controls)
1	Duration of the longest pause	Duration of the longest pause of 100ms or longer. If not such pause occurred, 0ms is recorded for this measure	0.988	0.899
2	Number of pauses	Number of pauses of 100ms or longer	0.987	0.906
3	Movement time	Complete movement time from target onset to the end of the successful click on the target	0.985	0.931
4	Verification time	The time interval between the end of a movement inside a target and the beginning of the click (i.e., the time when the mouse button was pressed)	0.909	0.9
5	Click duration	The time between mouse button press and release during the correct click on the target	0.907	0.94
6	Execution time	Time from the first to the last mouse movement (excluding any movement that occurred while the mouse button was pressed)	0.887	0.951
7	Click slip	Distance between the point where the mouse button was pressed down and where it was released during click on the target	0.825	0.758
8	Execution time variability	Coefficient of variation of execution times in a block of trials	0.808	0.899
9	Verification time	Standard deviation of verification times in a block of trials	0.799	0.915
10	Normalized jerk [4, 11]	$\text{normalized jerk} = \frac{(ET)^3}{v_{max}^2} \int_t \left(\frac{da}{dt}\right)^2 \mathrm{d}t$ where $\frac{da}{dt}$ is the jerk, ET is the execution time without pauses and v_{max} is the peak speed during the movement.	0.799	0.95
11	Execution time without pauses	Like execution time, but excludes pauses of 100ms or longer	0.75	0.943

A-T), 0.99 (healthy controls). Features related to time showed up to be the most reliable; these included duration of the longest pause, number of pauses, movement time, verification time, click duration, and execution time (with and without pauses). (Table 2) lists Hevelius measures that demonstrated excellent and good reliability for participants with A-T. Supplementary material lists the reliability of all 32 Hevelius measures for participants with A-T and healthy controls.

5.4 Acceptability of at-home assessments

We share participants' and caregivers' acceptability of using Hevelius at home. We draw on quantitative data from usage logs and qualitative data from participants' self-reports (responses about mood, alertness, and sleep on a 5-point Likert scale) and caregiver reports (responses to 5-point scale about tiredness and degree of co-operation; usage reports about issues). A summary of Hevelius usage by participants with A-T is shown in Table 3. In the rest of the section, we use "Pxx" to refer to the participant and the caregiver.

Table 3. Summary of at-home use of Hevelius by participants with A-T. *Severity* is the severity score assigned by a clinician. *# At-home sessions* counts the number of attempted sessions (*Attempted*) and those sessions (*Accepted*) that yielded measures that were not null/outliers; *Time taken* (measured in minutes) represents the median time taken by the participant during the pointing task over at-home sessions.

P id	Age (yrs)	Severity (0-4)	# At-home sessions			Issues reported
			Attempted	Accepted	Time taken	
P01	06	2.0	04	03	11	-
P02	13	2.0	12	10	05	-
P03	07	0.5	12	12	06	Accidentally switched windows, right-clicked; frustrated
P04	09	2.5	03	03	14	Got frustrated
P05	09	2.0	12	12	09	Clicks not registered
P06	06	1.0	12	11	09	Clicks not registered (thrice)
P07	10	1.0	09	08	07	Clicks not registered
P08	07	1.5	06	03	08	-
P09	15	2.0	12	11	05	-
P10	15	3.0	08	08	04	-
P11	12	2.5	12	12	09	Difficulty controlling the mouse
P12	10	2.5	05	05	06	Clicks not registered
P13	11	2.5	06	04	11	Pointing task froze; mouse difficult to use
P14	10	2.5	13	10	07	"it glitched" [sic]

5.4.1 Most at-home sessions yield measures and take a few minutes on the pointing task. Overall, participants used the tool at home for 126 sessions of which 111 sessions (88%) provided measures and usage reports from caregivers. Of the sessions that didn't yield measures, 06 sessions provided data that our analysis scripts couldn't parse; 04 sessions provided data that were outliers for the corresponding participants; 03 sessions comprised incomplete use; and 02 sessions had a technical glitch while participants used the tool. Caregivers reported 11 of 111 sessions as too long. The per-session median time for pointing tasks ranged from 4 minutes to 14 minutes. The median time on pointing tasks was less than 10 minutes for 11/14 participants with A-T.One caregiver added a note to "reduce practice time and number of rounds" (P11, Session 2) while caregiver for two participants requested "less dots" as well.

11 of 111 sessions were reported to have technical issues. Such issues included clicks not registered on the targets and participants making mis-clicks. Caregivers reported restarting the task to perform the task. One concern was when the targets appeared cut off on the screen; in response, the research team altered the pointing task systematically for all participants so the targets appeared in full on smaller desktop screens as well. Caregiver for P05 reported slowing the cursor speed and making the cursor bigger.

Caregivers for 03 participants also reported the participants being frustrated while clicking the targets with the mouse.

> "[Participant] move (sic) the mouse back and forth across the screen in frustration, as I'm sure you'll see in the results" (P3, Session 10)
>
> "Bigger dots would be helpful and less of them. Also the mouse is difficult to use, as his fingers keep hitting the rolling piece in the middle which causes google chrome to ask if we want to close out the program. The combination becomes frustrating for him." (P13, Session 4)

03 families also mentioned health and lifestyle challenges in using the tool regularly; lifestyle concerns included travel and sports tournaments. Some caregivers provided suggestions to improve the assessment. Caregiver(s) for P13

suggested numerous ways to improve the task such as including audio feedback and gamifying the task with a pointer as a super mario kart driving to the target.

5.4.2 Participant self-reports and caregiver reports about health and well-being did not better explain the variation in at-home assessments. A goodness of fit analysis estimated the proportion of variance explained in estimated severity scores by models that included three parameters: a unique participant code (nominal), at-home session number (ordinal), and caregiver & participant responses (ordinal) in that order. R^2 values demonstrate participant code explained 73.7% of the variance in estimated severity scores; adding the session number accounted for 76.2% of the variance. Further including caregiver and participant responses accounted for 79.5% of the variance.

5.4.3 Caregivers shared details about participant. Some caregivers provided additional details about the participant' health in response to a prompt about sharing current events for the participants to help researchers better understand the data.

> "[Participant] was standing still and fell at drama class and bruised left leg; did not wear CPAP 2 nights this week, had a sleep study with titration 1 night additional; Blood draw for bi-annual immune panel, 10 vials blood drawn." (P2, Session 3)
>
> "He still has some nasal congestion and cough, is doing breathing treatments to keep his lungs clear." (P5, Session 8)
>
> "She seems to have a cold with nasal congestion. She also had a low-grade fever off and on all week. " (P6, Session 2)

Some caregivers shared some theories about performance and compensatory strategies

> "Lots of exhaustion and wobbling this week. Not sure if we're seeing a regression in her condition or if she's just extra tired from all of the activities we have been up to." (P3, Session 11)

5.4.4 Participants developed strategies to perform the task. In 22 of 111 sessions, participants were reported to be altering their sitting posture while performing the pointing task. Some common heuristics emerged: participants used their non-dominant hand (hand not used for the pointing task) to stabilize themselves. Caregivers reported–sometimes across multiple sessions–that participants used their non-dominant hand to brace themselves on the on chair/bench they were sitting on (P3); to steady the wrist of the main hand (P6); to hold the table on which the laptop with the task was used (P5). Another strategy was to lean in closer to the laptop; 3 Caregivers reported that participants leaned forward to the screen (presumably) to see more clearly, especially for smaller targets.

6 DISCUSSION

Cost-effective, frequent, and unobtrusive assessments of health state is an important goal in health research [17]. In this paper, we performed at-home assessments for motor impairments with a recent computer-based system, called Hevelius, for quantifying motor impairments in the dominant arm. Hevelius presented participants with pointing tasks and produced 32 valid, reliable, and interpretable features from the trajectories of the mouse movements. In this section, we discuss unsupervised assessments and suggest broader avenues of engagement with health and HCI research.

6.1 Comparing supervised and unsupervised assessments

Our work extends the current understanding of measures of motor performance from the lab to unsupervised settings. Prior work has noted both opportunities and challenges with unsupervised sessions. While the success of "lab-quality"

pointing data in automatically detecting movement disorders is promising [13], one session of pointing tasks in the lab is not enough to develop realistic measures for variance of performance and error distribution [15]. Our results demonstrate that Hevelius' measures from unsupervised use are as good as measures from a supervised use in estimating clinically-meaningful ground truth.

Successful experimentation and data tracking in real-world settings demonstrates tension between scientific validity and lived experience [18]. Introducing a novel tool might increase these challenges if people struggle to use them. We suspect that the peculiar dip in the quality of data for unsupervised session#1 (r=0.47; Figure 3A) might have been due to people's challenges using Hevelius for the first time without any supervision. Further work can investigate whether such *first session issues* are common in remote deployments and if so, how might health researchers reduce such challenges (e.g. by providing remote supervision for the first session). Presence of outlier sessions also demonstrates the need to collect data over multiple sessions. We provided families with technical support to systematically resolve issues (e.g. for pointing task not fitting on small screens). Since some families reported participants' concerns with mouse use, future research can consider exploring technical infrastructures that might be more suitable to pediatric population.

Frequent, remote assessments are exciting but there might still be value in supervised assessments that goes beyond collecting high-quality data. In-situ participant observation is a key technique for developing a deeper understanding of people's interactions with technology [6]; however, performing in-situ observations in people's homes is infeasible beyond a small number of participants. Supervised use of a tool shows researchers whether users follow the prompts and/or perform tasks not explicitly mentioned. For instance, the primary author observed that participants altered their sitting posture while using Hevelius. After adding this as a prompt for caregiver reports during at-home use, the trend became clearer: in 20% of the sessions, participants demonstrated such compensatory strategies (e.g. leaning in to the monitor or bracing their non-dominant hand on furniture).

6.2 The potential for unsupervised assessments in clinical practice and research

By generating quantitative measures of people's motor performance, at home assessments provide potential value for multiple clinical processes by improving the quality and frequency of assessments. Assessment scales for motor impairments are typically ordinal with large differences among categories. Such scales intend to meet the goal of achieving acceptable reliability from noisy human assessments. However, they are of limited help in tracking slowly-changing diseases and evaluating interventions that have small effects [30]. Hevelius' granular measures can help clinical research by improving on existing coarse estimates of the severity. A related concern for doctors during telemedicine encounters is identifying subtle differences in patients' motor performance over video-based interactions [2]. At home assessments–like the ones supported by Hevelius–can enrich telemedicine by improving the specificity of such assessments without requiring clinician time. At home assessments can also potentially tackle order effects [5], such as recency bias, in patients' self-reports. For instance, many in-clinic visits for movement disorders happen once every six months. Quantitative, unsupervised assessments can reduce the reliance on patients' and caregivers' self-reports; instead, such assessments can provide objective measures and complement those with caregivers' reports of patient health and updates over multiple sessions. Our results describe how some caregivers share detailed reports about participant health.

Any future clinical use of unsupervised assessments must also attempt to avoid or minimize potential concerns. For instance, remote monitoring can increase work for clinicians; prior integrative review has found that patients expect providers to constantly monitor data to dispel their doubts [29]. Such assessments can also create novel concerns. For instance, frequent assessments of motor impairment could be confounded by cognitive efforts and motor learning [23].

Another challenge is potentially increasing caregiver burden. Caregivers spend a lot of effort taking care of people with disorders [1]; depending on them for unsupervised assessments can be more challenging in more longitudinal settings. While answering these questions was out of scope for our research, we suggest developing heuristics to better integrate unsupervised assessments in clinical processes.

6.3 Support from partner organizations like rare disease foundations

Sociotechnical systems can amplify the efforts of committed and knowledgeable individuals [35]. However, finding such individuals, getting them started, and keeping them invested requires complementary efforts. Additionally, prior research has noted the difficulty of finding participants for clinical trials for rare disroders [22]. Overall, Hevelius' success in collecting useful measures from unsupervised settings relied on both the design of the tool and our partners, specifically the rare disease foundation A-T Children's Project. Having worked with the patient community and multiple researchers, the rare disease foundation provided multiple contributions that are difficult to achieve for a small research group. First, the rare disease foundation assisted the research team in publicizing the study and finding participants. Second, the supervised use of our tool happened at a gathering of families organized by the rare disease foundation. Meeting multiple knowledgeable and interested families in one place would have otherwise been challenging. Additionally, such face-to-face interactions can also improve trust in electronic contexts [31]. Third, the foundation reminded participants when they did not use Hevelius (after receiving usage updates from the research team). For cases where such patient-researcher understanding/trust might be more nascent, not visible, or clearly lacking, researchers can better direct efforts towards better understanding the community. As our experience suggests, such trust-building and knowledge sharing can be mediated and accelerated by trusted organizations.

7 CONCLUSION

This paper reports an at-home longitudinal study of a recent computer-based system, called Hevelius, that quantifies motor impairments in the dominant arm [10]. Hevelius computes 32 measures from the movement trajectories and does not require expert judgement or age-matched healthy controls to compute severity scores. Our findings demonstrate that unsupervised use of Hevelius produces data that are as valid as the data obtained in supervised settings. Further, the data obtained at home demonstrate strong test-retest reliability. Lastly, participants and their caregivers contributed data without major concerns. Taken together, our results contribute evidence that it is possible to obtain valid and reliable quantitative assessments of motor impairments in unsupervised settings.

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